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RETARDED CHILDREN
CAN BE HELPED

DECADE OF DECISION

An Evaluation Report Prepared by
National Association for Retarded Children, Inc.
for
The 1960 White House Conference on Children and Youth

NATIONAL ASSOCIATION FOR RETARDED CHILDREN, INC.
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Foreword

The National Committee for the 1960 White House Conference on Children and Youth has invited each of the 500 national organizations with a major interest in children and youth to prepare for submission in September, 1959, an evaluation report summarizing accomplishments in its field and prospects for the decade ahead. In preparing this evaluation the national associations were urged to relate their activities and the developments in their field of interest to the theme and focus of the 1960 White House Conference.

The promotion of "opportunities for children and youth to realize their full potential for a creative life in freedom and dignity" is a purpose with which the National Association for Retarded Children readily allies itself. This theme and focus gives the structure to NARC's evaluation report. We have addressed ourselves to the accomplishments of the past decade and to the tasks ahead under each of the major headings encompassed under "personal and environmental influences", paraphrasing paragraph 1C of the full statement of the national theme. Here we deal with the heart of the NARC program under the suggested headings of family, religion, physical health, mental health, education, recreation and the arts, welfare, work and guidance and finally law and government.

Only highlights - and not all of them - could be included in reporting so diversified a subject which has undergone such spectacular metamorphosis in the decade just concluding, and which promises so much for the next.

THE THEME ADOPTED BY THE NATIONAL COMMITTEE FOR THE
1960 WHITE HOUSE CONFERENCE ON CHILDREN AND YOUTH

The purpose of the 1960 White House Conference is to promote opportunities for children and youth to realize their full potential for a creative life in freedom and dignity.

This effort will be based on:

1. Study and understanding of
 - (a) The values and ideals of our society;
 - (b) The effects on the development of children and youth of the rapid changes in this country and the world;
 - (c) And how family, religion, the arts, government, community organizations and services such as health, education, and welfare, peer groups, and the behavior of adults in their interactions with children and youth deter or enable individual fulfillment and constructive services to humanity.
2. Examination of the degree of achievement of previous White House Conference goals and recommendations.
3. Determination of the action that individuals, organizations, and local, state, and national government can take to implement conference purposes.

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I. Preamble

The year 1960 will be celebrated as the Tenth Anniversary of the National Association for Retarded Children. The birth and rapid growth of NARC is thus in itself one of the phenomena peculiar to the decade under review; it is a phenomenon which significantly affects the lives of the nearly two million children and youth of the United States who are mentally retarded in greater or less degree.

NARC has been both a producer and a product of changed attitudes towards mental retardation. It was created to promote the welfare of the mentally retarded of all ages and degrees of handicap wherever they might be and to develop the means of preventing this condition in children of the future. It is the only national voluntary citizen organization espousing these objectives.

II. How NARC Came Into Being

The movement on behalf of retarded children had its slow beginnings in the mid - '30's with the formation of a few localized groups in Ohio and Washington. The National Association was organized in September of 1950 when forty individuals, representing local associations in thirteen states, assembled in Minneapolis and adopted a constitution under which the National Association of Parents and Friends of Mentally Retarded Children came formally into being in February, 1951, after ratification by the first twenty existing local associations. Despite differences in organizational structure and immediate goals these pre-existing groups were impelled by their basic common purposes to join forces.

By the time of the 1951 Convention the following October, fifty-seven local associations had adhered to the new federation. By September, 1959, the organization had grown to 700 local member units distributed in forty-nine states (Alaska being the only exception) and having an individual membership of approximately fifty thousand individuals. State federations have been formed in 46 state.

Of the one-hundred-seventy "standard metropolitan areas" listed by

the United States Census Bureau, only eleven are not directly served by one or more units of the NARC. Hundreds of smaller associations reach out into the farm communities of Maine and Iowa and the mountain valleys of Idaho and upland California and the outlying islands of the Hawaiian archipelago. Member units have also been formed in overseas military installations.

Comparable organizations are developing apace in most of the countries of the British Commonwealth and in Norway, Sweden, Denmark, Holland, France, Switzerland, Turkey, Israel and Japan. An international federation is almost certain to be formed within the next decade.

III. Why NARC at Mid-Century

In view of the stress being laid by the 1960 White House Conference planners on social, cultural and economic changes, it may be appropriate to explore here briefly the question, "Why did a parent-inspired national voluntary movement in behalf of America's retarded children and adults emerge when it did?"

The half century between 1870 and 1920 was, in fact, a fertile one both scientifically and socially for the mentally retarded. The first public school class for the mentally retarded was opened in Providence in 1896, and the special class had become an accepted and established part of many of the major city school systems by 1920. Residential institutions for care and training were established or expanded in many states during the same period. The scientific study of the behavior of the mentally retarded flourished. Partly because of the high mortality of the most severely handicapped, scientific and social attention focused particularly on the mildly retarded. Both science and society "discovered the moron" in the year of the first White House Conference but whereas science reacted on the whole with constructive curiosity, society, on the other hand, tended to react with something less than constructive anxiety to the new "menace", an anxiety which resulted in ill-founded enthusiasm for programs of segregation and sterilization.

The schools, however, remained faithful through the third decade, and programs continued to spread. This era appears to have come to its climax in 1930 when the rights of the handicapped child to education were set forth in the voluminous publications of the 1930 White House Conference, whose findings were still being quoted in college lecture halls twenty-five years later. Even such dedication was not proof against the combined effects of the depression and the staggering increase in total school population of the '30s. From the mid-30s on, enrollment of mentally retarded pupils in special classes declined not only absolutely, but also proportionately until the late '40s.

Somewhere along the line also, the inclusiveness which had characterized the school programs of the first quarter of the century began to be modified. Sometimes by law, sometimes by interpretation, sometimes just by gentlemen's agreement among administrators, special classes for the mentally retarded began to be restricted to those defined as "educable", usually designated as I.Q. 50 or above.

Soon also, child guidance clinics, established earlier in a number of states primarily for the purpose of helping the mentally retarded began to turn their attention away from the retarded favoring now the emotionally disturbed, for whom the new psychiatry seemed to offer more results. The edge began to wear off the hope of the first quarter century.

In the meantime the hospitals, the obstetricians, the pediatricians and the other maternal and child health workers had been collaborating to produce spectacular reductions in infant mortality. The introduction of anti-biotics immediately following World War II saved additional young children from respiratory and gastrointestinal diseases. These improvements in public health appear to have differentially favored children with congenital handicaps such as mongolism. These trends, superimposed upon the high post war birth rate, brought us to the opening of the second half century with a significantly larger number of young, severely mentally retarded children, both numerically and proportionately, than at any time in our previous history.

The majority of these more handicapped youngsters were "trainable" i.e. capable of profiting by a modified program of group instruction slanted toward goals of social adjustment, and the development of language and manual skills. Yet, with the exception of three or four isolated cities and a few smaller communities, these children were being rejected right and left by the public schools.

Parents of those who were too severely retarded or had complicating disabilities precluding classroom participation were being almost universally advised by physicians to place their children in residential facilities only to find that thousands of other children were already enrolled on waiting lists ahead of them. Because of the high costs of long-term residential care, 90 to 95% of families must seek it in a public institution. Parents whose children had secured admission to one of the state-operated "schools" or "homes" housing anywhere from five hundred to five thousand individuals of almost all ages, were often shocked at the overcrowding, understaffing, poor maintenance, minimal food, and unsanitary conditions not to mention the enforced inactivity of the majority of "patients" which did nothing to enhance the "freedom and dignity" of the handicapped child and little more for those who, in spite of everything, might be struggling to care for him.

War, depression and paradoxically, modern medicine had conspired to bring about an acute multifaceted social crisis to which the social response was the formation of a community-based, state and nationally coordinated movement. This movement on behalf of the "Forgotten Children", already somewhat overdue, having been itself inhibited by conditions prevailing between 1935 and 1945, flowered readily in the relatively more favorable environment of the last decade. Perhaps it was no coincidence that it was born in the year of the mid-century White House Conference, with its emphasis on citizen participation.

Although still relatively modestly financed, especially in relation to the size of its task, when compared with other major voluntary health and welfare organizations, NARC has, nevertheless, come of age and come to stay in nine breathless years.

IV. Relation of NARC Program to Conference Theme

By focusing on "opportunities for children and youth to realize their full potential for a creative life in freedom and dignity" the national committee has spotlighted an issue which is not only germane, but central to the interests of NARC, most of whose activities are directed toward creating such opportunities for the mentally retarded.

1. Values and Ideals

Our society is not always entirely consistent in applying its values and ideals to the mentally retarded. On the one hand, we affirm the value of each individual, his right to individual fulfillment and to a useful social role in accordance with his abilities; on the other hand, stress is placed on economic and scholastic achievement, physical ability and perfection, and on competition in feats in which the mentally retarded can seldom emerge triumphant. We are still asking the retarded child to value himself and value a society which too often devalues him. ("Why should we spend money on the retarded when we are not doing enough for the gifted?" or: "Of course the retarded youngsters should have their school, but not in our neighborhood.")

2. Effects of Change

By the very nature of his handicap the retarded child is slow to adapt to changed circumstances, sometimes slow even to perceive that they have changed. The problems presented by mobility, urbanization, uncertainty as to acceptable mores, may all confront the retarded child in exaggerated form. Two characteristic effects are worth special mention; (a) since the retarded individual must be prepared more explicitly for his occupational future, he will be especially vulnerable to

changes in the structure of available employment to the extent that these cannot be foreseen by his teachers; (b) servicemen's families and other highly mobile parents are confronted with a particularly difficult task of providing continuity of programming for their handicapped children and also of securing those services to which their eligibility may be restricted by residence laws.

3 o Personal and Environmental Influences

Since with present knowledge little can be done to cure or treat (medically) the condition of mental retardation once established; it is to the manipulation of personal and environmental influences on retarded children and youth that the NARC directs a major part of its program, which will be analyzed according to the suggested components in the following section.

V. The NARC Program 1950-1960

Part A - "To promote the welfare of the mentally retarded".

It may be worth noting that NARC's program of service to the retarded has changed shape somewhat in the decade; it started out as comprehensive but somewhat elliptical, polarized around the two foci of needed day schooling and equally needed residential care facilities. By 1954 it had become decagonal, with the emergence of a "10 point plan", but by 1958 it had taken on the holistic simplicity of a "well rounded program" . (See chart)

In any case, mental retardation being all pervasive in its influence on the life of the individual, the mission of NARC encompasses the f a m i l y , r e l i g i o n , h e a l t h , e d u c a t i o n , r e c r e a t i o n , w e l f a r e , l a w and g o v e r n m e n t , w o r k and g u i d a n c e . A definitive evaluation of the accomplishments of the last ten years and tasks yet to be accomplished in each of these areas would require a volume. The more there is to be done the less time there is to write of it. Therefore only selected highlights are outlined below, as indicative of trend.

These have been chosen without regard to the well springs of action. NARC may serve directly or it may serve as well by creating the environment in which others may achieve; it is to the program objectives rather than authorship that we address this evaluation.

A. The family

Accomplishments for the family

1. Physicians" advice: Reports from parents at the time of the

formation of NARC, while not quantifiable, indicate that it was common practice among physicians at that time to couple a diagnosis of mental retardation with advice to institutionalize the child promptly. This advice was often, given without consideration of its practicability or of the responsibility of the parents to evaluate and decide for themselves. One of the hopeful signs of the last decade has been the increasing frequency with which articles have appeared in professional journals, including medical journals, advocating a more individualized approach and in particular inveighing against advice to institutionalize in infancy or early childhood except in extraordinary circumstances.

2. Diagnosis and guidance: The family who suspects one of its children of being mentally retarded needs a comprehensive coordinated evaluation of the medical, psychological, social and educational factors, interpreted to the parents in language and at a pace they can understand, coupled with practical suggestions for the care and training of the child related to actual, available resources. To be properly effective such a service must be rendered by specialists who have a major interest in the retarded child and a specialized knowledge of his problems. There is not known to our association any facility in existence prior to 1949 which met all of these criteria. The development of such clinical facilities in the past decade is indicated by the following:

<u>Date</u>	<u>Number of Clinics</u>
January 1st, 1949	0
" " 1955	33
" " 1959	70

The first clinics were initiated for the most part at the urging of local associations for retarded children, but the second and more difficult half of this development owes much to the special grant program of the U. S. Children's Bureau.

3. Parent Education: In 1950 a most serious problem facing parents of retarded children was the lack of helpful information on the problem of mental retardation and particularly on home care and management. Since then many communities have developed parent education programs. In a recent survey NARC found a distinct trend toward parent-motivated discussion groups (as opposed to lectures), with 44 out of the 75 programs providing for series of 6 or more meetings.
4. Parent Education Literature: The editor of a reading list for parents in 1950 found only two pamphlets (one of them

Canadian) and one chapter of a book addressed directly to the parents of retarded children. NARC's 1959 revision of "Windows of Understanding", its reading list for "new" parents, lists eighteen books and pamphlets written expressly for parents of the retarded, together with five book-length, first-person stories.

5. Studies of family living with retarded: Although in 1950 brief generalized statements in psychiatric text books about the disintegrating effect of a mentally retarded child upon his parents and siblings were quite common, no substantial research had been done on this problem. In 1959 a monograph based on a three-year study entitled "Effects of a Severely Mentally Retarded Child on Family Integration" was published, which among other things indicated the inappropriateness of unqualified generalizations.
6. Peer Groups: Increasingly reports received from NARC state and local units, reveal the role being played by normal youth in molding the environmental influences on the retarded young person. Youthful volunteers help to staff day and residential camps, participate in teen-age canteens for the retarded, help to raise funds, write term papers or give talks before social studies classes and finally elect careers of service related to mental retardation. There is no doubt that these young people, shorn of prejudice as they are, or as they become, bring to the retarded with whom they come in personal contact a particular kind of reassurance.

Tasks Ahead in Relation to the Family

1. Bringing comprehensive competent evaluation and guidance services to parents in rural areas.
2. Modifying the content of out dated high school texts in social studies, which by purveying unscientific ideas prejudicial to the mentally retarded, not only cause pain to their adolescent siblings, but also sow the seed of unnecessary shock and shame for those youth who will shortly become the parents of the mentally retarded children of the next decade.

Religion

Accomplishments in the Field of Religion

In 1952 NARC sought from the major national bodies concerned with religious education of children, help and guidance in providing suitable instruction for the mentally retarded

of varying degrees of intellectual limitation. Little or nothing was to be had. By 1959 we find throughout the country hundreds of classes through which Roman Catholic, Protestant and Jewish children are instructed in the essential truths of their faith. The National Catholic Education Association established its department of special education, and the National Council of Churches issued several publications stressing the churches' responsibility to the handicapped, including the mentally retarded. Institutes for religious teachers and for clergymen have been held in various parts of the country; books are appearing in which the role of religion in the life of the retarded child and his family are discussed; new day and residential schools, usually non-sectarian in admission policy, are being organized under Roman Catholic, Lutheran, Presbyterian, Episcopalian, Jewish and other auspices.

Tasks Ahead for Religion

1. Development of really appropriate instructional materials for use with mentally retarded children.
2. Better preparation of clergymen of all faiths to meet the spiritual needs of the families of the retarded.
3. Cooperation of the religious bodies and government in meeting more adequately the religious needs of the institutionalized retardate.

C. Physical Health

Accomplishments in Physical Health.

1. At the beginning of the decade children with orthopedic handicaps who were also mentally retarded were frequently excluded from crippled children's services. Substantial improvement has been noted. (More precise documentation is available from U.S. Children's Bureau.)
2. Pediatric internships in facilities caring for the mentally retarded have substantially increased during this decade.
3. In 1950 there were few dentists prepared to accept and treat a severely involved mentally retarded child who could not cooperate. Extraction was often the only kind of dental treatment offered. During the past ten years special institutes for dentists have been held and a number of specialized dental clinics established.
4. Public health nurses have become increasingly aware of the role that they can play in assisting the family of a young

mentally retarded child to train him in feeding, dressing and toileting.

5. A conference on nutrition of the retarded in institutions was supported by the Children's Bureau.
6. Prevention of brain damage by early intervention with special surgery, special diets and other means is becoming recognized as a responsibility of the practicing physician.

Tasks Ahead in Physical Health

1. While certainly diminishing, there is still a substantial number of physicians who consciously or unconsciously reject the retarded child, as a patient whose physical well being is not fully worthy of their attention. This is probably a matter of medical education.
2. The handling of the severely retarded child who is hospitalized for surgery or acute illness has been little studied and the insecurity of nurses faced with this problem often compounds an already difficult situation.

D. Mental Health

Accomplishments in Mental Health

1. Probably the most significant contribution to the mental health of the mentally retarded child has been made by NARC itself through public education and through the opportunity which it affords to parents to associate together and share experiences. The self-respect and self-confidence thus engendered in parents, together with the provision of practical services by the communities, local and state, made possible better over-all mental health for the mentally retarded.
2. In 1950 mentally retarded individuals, even of the higher ranges of intelligence were frequently rejected for treatment by mental health clinics and private practitioners on the assumption that they could not benefit by psychotherapy. During this decade these attitudes have substantially changed, as evidenced by the wide circulation of such books as "Psychological Problems in Mental Deficiency" (Sarason) and "Counselling and Psychotherapy with the Mentally Retarded" (DeMartino). (In 1957 the regional office for Europe of the WHO sponsored a ten-day seminar devoted entirely to the mental health of the mentally sub-normal child.)

Tasks Ahead in Mental Health

1. Although mental deficiency has been traditionally assigned by medicine to the domain of psychiatry, few psychiatrists are adequately trained in the intricacies of this complex field.
2. The frequent categorization of mental retardation as "a mental health problem" by layman and professionals alike, has inhibited other specialists from recognizing and assuming their proper responsibilities. (Example, a state department of health which replies to a questionnaire on its services to the mentally retarded by stating categorically that the state department of mental hygiene "takes care of everything".)

E. Education

Accomplishments in Education

Short of primary prevention, education offers the greatest hope for the mentally retarded. Progress during this decade has been spectacular.

1. In 1949 twenty-four states and the District of Columbia had state legislation providing for special classes for the mentally retarded in the public schools. In 1959 forty-eight states and the District of Columbia had such legislation. (States without legislation are Arizona and Alaska, of which the former had classes in several major cities.)
- 2 . In 1950 no state had laws specifically encouraging local districts to provide for the "trainable" mentally retarded, (roughly characterized by I.Q. 25 to 50), although a few states tolerated and even subsidized such local classes as might be initiated by local school boards under general, broad-purpose legislation. By 1959 twenty states had specific mandatory or permissive legislation under which such children are provided for in the local public schools. An additional seventeen states by administrative regulation or interpretation sanction such classes as being authorized under more general laws.

Laws do not create classes by themselves, however. The following table gives a rough gauge of progress.

Public School Enrollment of Mentally Retarded
in Special Classes

	<u>1940</u>	<u>1948</u>	<u>1953</u>	<u>1958*</u>
Educable	(not		109,903	
	(differ-			
Trainable	(entiated		<u>4,662</u>	
Total	98,416	87,030	113,565	

% of total
public school
enrollment .38 .36 .39

*To be filled in from USOE figures about to be released.

3. During the decade an important study of teacher preparation was made by the U. S. Office of Education. It revealed that in 1954 forty colleges and universities were offering a sequence of at least three courses including supervised practice teaching to prepare teachers of the mentally retarded. Since then the number of such curricula has substantially increased and summer sessions have become very widely available indeed.
4. An analysis of the current and projected need for teachers of the mentally retarded was made by NARC in 1956 and submitted to the Congressional committees considering the bill which, in 1958, became Public Law 85926, and has now been activated by means of an appropriation. Its purpose is to encourage expansion of education of mentally retarded children through grants to institutions of higher learning and state educational agencies to improve and increase the training of personnel.
5. Extending school **programs accentuates** the need for further research in techniques and substance of education for the retarded. The inauguration of the Cooperative Research Program under the U. S. Office of Education in 1955, with the earmarking of a substantial fraction of the funds for research in the education of the mentally retarded is another significant accomplishment of this decade.
6. Nursery schools for pre-school children and day care centers for children too severely retarded to qualify for program of public school instruction are part of the larger education picture designed to permit each mentally retarded child to achieve his full potential, however limited. NARC

is currently surveying the rapid developments in this field.

Tasks Ahead in Education

1. Finding more effective ways of reaching the extremely severely retarded child on an individual (non-school) basis.
2. Better financing of special classes in states which have been slow starters.
3. Greater reciprocity among states in teacher certification standards, which in turn would imply a raising of the standards in many states.
4. Improved coordination between education and vocational rehabilitation agencies in preparing the mentally retarded for the world of work.
5. Emphasis on quality in teacher preparation based on depth and breadth in this special competence on the part of college faculty members.
6. Better orientation of education administrators to the goals and uses of the special class.

F. Recreation and The Arts

Accomplishments in Recreation and the Arts

1. So far as is known the first summer day camp for mentally retarded children was organized in 1950. By 1955 there were fifty-five such day camps; in 1959, 150 were reported. A number of residential camp programs have also been established.
2. A cooperative effort between NARC and the National Recreation Association revealed that between 1954 and 1958 the number of recreation programs, such as summer playgrounds, teen-age canteens, and swimming activities, sponsored by municipal public recreation departments at least trebled.
3. A manual on swimming for the retarded was prepared in cooperation with the American Red Cross Water Safety director.
4. Although Boy Scout troops in residential institutions date back to the late 20s, it is believed that the first troop of retarded scouts in the community was formed in 1950. Now one-hundred-fifty troops of mentally retarded boys (including cubs) are registered with the Boy Scouts of America, Comparable advances in girl scouting are recorded.

5. In the spring of 1959 a Milwaukee museum devoted an entire exhibition to art of the mentally retarded.

Tasks Ahead in Recreation and the Arts

1. Orientation of recreation workers and directors to the place of the retarded in community recreation programs, and particularly to the factors which determine the extent to which any particular child should be integrated with or segregated from normal children in group activities.
2. Research on safety in recreation for the retarded - in design of equipment and of activities.
3. Analysis of recreational activities and needs of retarded adults of various levels as a guide to the recreation skills and preferences which they should be encouraged to develop as children.
4. Development of recreational activities appropriate to very severely retarded children in the home, in community centers, and in institutions.

G. Welfare

Accomplishments in Welfare

1. Casework: Perhaps nowhere more than in the field of welfare have we seen the philosophy of segregation of the retarded reflected, not merely in arrangements for his physical isolation but also in the administrative structures of state and local government. It has seemed that the retardate must either be capable of being treated as a "person" whose problems can be dealt with by a welfare worker with a "generic" approach, or else the agency should wash its hands of him and turn him over to "the people in charge of institutions." If the institutional agency finds it either undesirable or impossible to institutionalize the child, it would presumably have to set up its own foster home or other supervisional program. With the outstanding exception of Minnesota, whose community program for the retarded was born within its child welfare services forty years ago and managed to survive the dark ages of the second quarter century, the attitude of "let the institution do it; it's their job" seems to have been prevalent in child and public welfare agencies, wherever substantial services beyond financial grants were seen as necessary.

It is therefore significant that, during the last decade

a specialist in mental retardation was placed on the staff of the child welfare section of the U.S. Children's Bureau.

the Children's Bureau initiated a study of the prevalence of mental retardation in the case load of public welfare agencies.

the National Conference on Social Welfare of 1959 included four sessions dealing specifically with problems of the mentally retarded.

a number of case workers have publicly deplored the inadequacy of their professional orientation towards problems of the retarded.

2. Social Security Amendments: Of great importance to the dependent retarded youth and his family were the 1956 amendments to the Social Security Act which extended survivors' benefits to a permanently disabled child beyond the age of 18.

3. Residential Care: State governments are now paying over \$200,000,000 a year for the care of approximately 150,000 mentally retarded or epileptic individuals in public institutions. In 1950, 46,000 or about 37% of those than in institutions were under 21; the proportion as well as the gross has undoubtedly increased in the past decade, since a general trend to earlier admissions of more severely retarded children has been noted. Between 1950 and 1957 public institutional capacity for the retarded increased by approximately 10,000 beds. Although accurate statistics on waiting lists on a nationwide basis are not presently available, it appears that new building has merely kept up with demand without substantially decreasing the back-log. (At mid-decade there were between 10,000 and 15,000 retardates awaiting admission.) Space is most acutely needed for severely retarded young children at the present time. Although some 17 new institutions were created during the decade (with 11 more on the boards), leaving Nevada and Alaska as the only states without separate state operated residential facilities for the retarded, too much of the new capacity was achieved by enlarging already overly large institutions.

There has been considerable experimentation with building design. One state sent its architect, a professional educator, and a member of the Legislature on a nationwide tour to look at new buildings and consult with those administering residential programs, prior to drawing up

plans for a new institution. Despite interest and talk, however, basic philosophical concepts are still confused; there is still inadequate differentiation between the needs of the higher grade individuals for whom the institutional training program is a way-station on the way back into society, and the severely retarded for whom it may have to be a permanent way of life; there is inadequate communication between architects, superintendents, people who actually work in the buildings, and experts in heating, lighting, mass feeding, communication systems and other specialists in the logistics of the physical management of institutions. (Superintendents are usually physicians or educators.) Ways in which building design can minimize housekeeping and thus maximize the amount of time that attendants can spend caring for the social and emotional needs of children have not been fully analyzed.

Programming has undoubtedly improved in the majority of institutions, although not spectacularly, during the decade. of the approximately 27,000 educable and trainable children of school age in residential institutions in the early part of the decade, only about 22% were enrolled in educational programs, notwithstanding the fact that the opportunities for education are often held out as a principal argument for removing such children from their homes. For comparative figures we must await the 1960 national census, but one can infer, from such indirect information as the increase in the number of teachers employed by institutions, that educational programs therein are being expanded. Recreational activities are also improving, as have medical and psychiatric care and social service.

Relations With Parents, individually and collectively, have undergone significant and recognizable changes in most states. Most institutions for the mentally retarded have been primarily "open institutions" in the sense that they are not walled or barred. (There are some deplorable exceptions.) Today, however, they are opening inward as well as outward as the frequency of visiting by parents and citizens increases. The development of volunteer service programs within institutions for the mentally retarded constitutes another important advance during the decade.

The period 1950-1960 has seen the advent of both tranquilizers and TV in most institutions, on the whole for the better, although not without certain attendant hazards for those who mostly sit and wait.

The decade has also seen considerable agitation for the reform of the various state systems of charges to parents for the care of their minor and adult children in residential institutions. Whereas most states admit any eligible child to a school for the blind, deaf or delinquent without charge either for tuition or maintenance, in all but four states, parents are expected to pay, "in accordance with their ability" up to full per capita costs for all services including education, recreation etc. In most cases the obligation continues for life and in some states liens accumulate against the parents' estate for the difference between the maximum charge and the actual payment. Leaving aside inequities and inadequacies in the actual administration of these laws, the basic "values and ideals" on which they appear to be based certainly require some clarification. The discrepancies are accentuated even more when one notes that in most states a parent responsibly desiring to have his child admitted to a state institution must have an order of commitment by a court, which substantially transfers legal custody if not actual guardianship to the state and leaves the parent few legal rights in determining his child's future from that point on. At the present time the "pay plans" have been recently revised or are under active review in at least eight of the larger states.

4. Private Institutions; Although there are about 200 private residential homes and schools for the retarded, housing from 5 to 500 children and adults each, these institutions account for only about 5% of the total institutionalized retarded population. Standard setting and accrediting of such institutions often falls in the no-mans-land between health, welfare, mental health, and education agencies. NARC is currently conducting a survey among the states to determine how many states have a licensing and inspection service, in what agency it is lodged, and what types of standards are used.
5. Community Planning: The advent of the well-rounded or multi-phase program brings with it a responsibility for local and state planning bodies, voluntary as well as official. It is heartening to note that in cities as widespread as Los Angeles, Miami, Richmond and Chicago, for example, the local council of social agencies has initiated an objective look at the totality of services available from specialized and general purpose agencies to the retarded children, youth and adults of its community.

Tasks Ahead in Welfare

1. Action on the problem of management of the defective delinquent: The three states which have done substantially more than wring their hands about this problem (Massachusetts, New York and Minnesota) have not come up with solutions that can be followed with confidence by others; nevertheless there is general agreement that specialized programs must be provided for the individual whose intellectual subnormality is accompanied by persistent anti-social behavior, that these individuals the majority of whom are adolescents and young adults, must be provided for, not only for their own sakes but also for the sake of those less offensive with whom they are now mingled in residential institutions.
2. Case studies of adoptive mentally retarded children - why they were adopted, under what auspices, by what kinds of people and what were the outcomes.
3. Assurances that the retarded child without parents will have the benefits of personal guardianship; provisions for competent public guardianship where suitable private guardianship is not available.
4. Projections of future need for residential care of the severely retarded based on analysis of changing trends in the characteristics of children for whom such care is sought.
5. State planning based on such projections, and on a more penetrating study of the physical and social need of the grossly handicapped, needs which, despite felicitous phrases to the contrary, differ substantially from those of ordinary human beings who can speak and act for themselves.

H. Work and Guidance

Accomplishments in Work and Guidance

1. World War II produced one positive result for the retarded among so many negative; it gave them a chance to show their capabilities in industry and in the armed forces. (It is said that the successful retarded soldier was the one who had insight into his own limitations, an important observation for those who guide them.)
2. Vocational rehabilitation of the mentally retarded as a major cooperative effort of official and voluntary agencies, local, state and national, became possible with the amendment in 1947 of the existing federal Vocational Rehabilitation Act. While there are still some states which do not

make enthusiastic use of the federal assistance provided, the increase in the number of individuals being habilitated nationwide has been spectacular. (We do not have exact data on the number who are under 21.) This has been accomplished in the main by two types of service:

- (1) Vocational counselling, with special reference to those leaving school, and
 - (2) The establishment of occupational training centers and sheltered workshops oriented to the needs of the mentally retarded.
3. While it is certain that a careful search of some of the multi-purpose sheltered workshops of 1950 would have revealed a few high grade mentally retarded clients, those who in the early '50s sought to lift the mentally retarded of marginal ability across the border line from dependence to independence, (or at least partial self support) found no prototypes for what we have today. There were lessons to be learned from the workshops already established for the blind and physically handicapped, but in most cases the personnel who had been successful with these partial disabilities found it hard to adjust to the less tangible, more pervasive, and more time consuming intellectual and social handicaps of the mentally retarded.

Today, however, NARC is in touch with at least 100 sheltered workshops and training centers for the mentally retarded which offer real resources for youth from 16 to 21, as well as for young adults. Most of these workshops receive direct or indirect assistance from state and national vocational rehabilitation agencies; 17 of them are currently conducting research or demonstration projects supported by federal grants. Somewhat more than half of the known workshops and training centers which serve the mentally retarded are operated by member units of NARC, the rest by a variety of community voluntary agencies. It has been repeatedly observed in these centers that I.Q. is much less highly correlated with placability in competitive employment, or productivity in the sheltered environment, than with school achievement.

Tasks Ahead in Work and Guidance

1. Extension of the concept of "feasibility" to permit the rehabilitation techniques developed in rehabilitation centers and workshops to reach those who would benefit by virtue of becoming less personally dependent and less of an economic burden, even though not actually capable of

earning. (An individual who can feed himself is less of an economic liability than one who is not, quite aside from humane considerations.)

2. Collaboration between schools, rehabilitation agencies and social agencies in establishing realistic goals toward which the retarded youth may be systematically directed.
3. The provision of living arrangements for the retardate who can hold a job but may not be strong enough to live quite alone.

I. Law and Government

Accomplishments in Law and Government

Developments in this field in the past decade fall in four areas:

(1) Concern with the legal status of the retarded individual before the law; (2) examination of the structure of state services, including questions of coordination; (3) interstate cooperation; and (4) the development of a federal program: by major agencies of the Department of Health, Education and Welfare, with generous support from Congress.

1. In the area of status of the individual we note:
 - (a) recognition (with relatively little achievement to date) of the desirability of making voluntary admission rather than court commitment the procedure of choice when care of the mentally retarded minor is sought in a state institution;
 - (b) constructive discussion and thought concerning the rights and responsibilities of the mentally retarded who may have been engaged in or accused of criminal acts.
2. The structure of government and the need for interdepartmental coordination at the state level has been a principal or ancillary concern of at least 17 special state legislative or gubernatorial commissions appointed to review one or more major aspects of the state program for the mentally retarded. A schematic analysis was made by NARC in 1959 of the activities of those commissions which were active between 1956 and 1959.
3. Interstate cooperation was exemplified by a unique two-day conference on state government responsibilities to the mentally retarded conducted by the Council of State Governments in November, 1958.

The Interstate Compact on Mental Health developed in 1955 and now adopted by some 15 states facilitates interstate transfer of mentally retarded individuals who have been

admitted to a state institution, but whose welfare would be better served in another state for some reason, such as change of family residence.

4. The establishment in the Department of Health, Education and Welfare in 1956 of an interagency coordinating committee with Dr. Joseph Douglas as chairman, signified a major intensification of effort of the Federal Government towards stimulating and assisting state and local governments and private organizations better to serve the mentally retarded. Since the HEW is itself the best authority on its activities, it would be presumptive of NARC to elaborate on this program except to remark that its impact has been felt in every corner of the country. A significant document relating to this development is "New Directions for Mentally Retarded Children - a Report of a Conference Convened by the Josiah Macy Junior Foundation at the Request of the Interdepartmental Committee on Children and Youth and held at Princeton, New Jersey, February 26th to 29th, 1956."

Tasks Ahead for Law and Government

1. Further basic analysis of the application and applicability to the retarded of present laws relating to "mental incompetence" guardianship of the person and property of children and adults, criminal responsibility, and commitment or detention of the retarded, from the point of view of both the principle of *parens patriae* and the principal of individual liberty and "freedom and dignity" for all children.
2. Perfection of uniform methods which can be adopted in all public agencies for recording and analyzing statistical data relating to retardation, particularly in the field of public health, welfare and education.
3. Development of a better rationale for sharing the costs of services to the retarded as between the individual or family and society on the one hand, and as between the various levels of government on the other.
4. Research on and application of better methods of making every public dollar appropriated yield the most in service for the retarded.

VI. The NARC Program 1950-1960

Part B - Prevention

Perhaps it was an oversight on the part of the National Committee to omit "research" among the list of environmental influences.

Certainly in relation to mental retardation, it is a vital influence today in changing the world for children. Concerned as it is that the retarded children of today will be helped, NARC has nevertheless devoted major attention to reviewing the causes (biological, psychological and social) of mental retardation, and counts as a major achievement of the decade the publication of the volume Mental Subnormality by Doctors Masland, Sarason and Gladwin. A book reporting on a three-year survey sponsored by NARC, it reviews the dozens of known and suspected causes of mental retardation and outlines the directions in which research should now be pursued to uncover additional causes and to effect prevention of mental retardation at its many points of origin. The pursuit of the biological causes will take scientists into almost every branch of basic medicine. From the study of psycho-social factors there emerges a clearer concept of the role of cultural, emotional and educational deprivation, which if sustained, can permanently aggravate or even cause an irreversible depression of mental development with mental retardation as the end product. The significance of the Sarason-Gladwin section of the report has been since underlined by the subsequent publication of the results of a six-year study of pre-school children, done under the direction of Dr. Samuel A. Kirk. Kirk showed that children who are mentally retarded and who suffer the additional handicap of environmental impoverishment have a better chance for sustained school achievement if provided with a well directed pre-school educational experience. Among the landmarks in research of this decade one must also rank high the establishment and rapid growth of the National Institute of Neurological Diseases and Blindness concerned as it is with most of the basic biological causes of mental retardation.

Tasks Ahead in Prevention

1. Vigorous support of research in the following principal areas in which research is important with respect to mental retardation.
 - Area A. Research in etiology, prevention and treatment;
 - Area B. Research in accurate evaluation of the handicapped individual in mental, physical, emotional and social spheres;
 - Area C. Research in the development of effective training techniques, such as would permit the individual to develop his fullest potentialities, and

Area D. Research to determine the best framework with in which his teaching, training, living and working can be most effectively carried on.

2. Additional efforts to assure that each new discovery will be applied at the earliest possible moment to the prevention of lifetime disability. During the past decade we have learned how to prevent mental retardation due to hydrocephalis, due to phenylketonuria, galactosemia and certain other specific disorders, but there are still children being lost to these diseases through lack of early detection or quick availability of preventive measures. Prevention of mental retardation due to psycho-social factors will be still more difficult, but a beginning could be made by more assiduous screening of children referred for early institutionalization.

VII. The Basic Ingredient: Personnel

The well-rounded program clearly requires a large number of people with a great variety of professional and semi-professional skills. Some of these needs are well documented (see U.S.O.E. study on Competencies of Teachers and NARC study of "The Need for Professional Personnel in Fields Related to the Education of Mentally Retarded Children"), of others we have the merest guesstimate. For example, the Joint Information Service of the American Psychiatric Association and the National Association of Mental Health reported in "The Staffing of Institutions for Mental Defectives" that there was great variability reflecting little scientific study in the estimates of institutional administrators as to their needs for the various kinds of professional personnel. All reflected a universal sense of inadequacy, however.

Strides are being made in personnel training, however. In 1954 there were only four colleges and universities providing training programs for the new profession of rehabilitation counsellor; by 1958 there were thirty such universities enrolling some 500 graduate students in this important field. The American Association on Mental deficiency and the Council on Social Work Education are jointly working out recommendations for curriculum materials in this field for social students. During this decade for the first time a clinical pastoral training program for chaplains was inaugurated in a state institution for the mentally retarded. A unique program for the preparation in the field of mental retardation was established, at the George Peabody College for Teachers with a grant from National Institute of Mental Health.

Fortunately both lay and professional people with new ideas and new skills are joining the ranks daily. They are thinking, talking, reading and writing. (Between 1950 and 1959 the American Journal on Mental Deficiency doubled the number of pages published annually and the new newspaper Children Limited attained a circulation of 45,000.) The retarded, like others, need a place to live, a place

to learn, a place to work, a place to play, a place to worship, but most of all they need people. Between 1950 and 1960 more people than ever before learned about, thought about and did something about the mentally retarded. To sustain this rate of progress is the task of the next decade.

9/1/59

If you are interested in the mentally retarded and current advances on their behalf in such varied fields as education, parent counseling, vocational rehabilitation, research, federal and state legislation, you should be reading CHILDREN LIMITED.

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